

Children and Youth with Special Health Care Needs

Network Newsletter

News, policy updates, resources, events, and advocacy opportunities

HOME- AND COMMUNITY-BASED CARE

Webinar: Personal/Attendant Care - What Does it Mean and Who Qualifies?

- DATE** Wednesday, November 8
- TIME** 10 to 11 a.m. Pacific Time
- SPONSOR** Team Select Home Care & The Unforgotten Families
- DETAILS** Speakers will present a general update on personal/attendant care, including how family members may qualify to be paid caregivers, followed by a Q&A session. [Register](#).



Materials now are available from the Manatt webinar [Working Across the Health Care Ecosystem: Successes, Challenges and Best Practices for Delivering Care at Home](#).

HEALTH EQUITY

American Academy of Pediatrics Policy Statement: Optimize Medicaid and CHIP to Promote Equity in Child/Youth Health

In a newly released policy statement, the American Academy of Pediatrics calls for several foundational changes to Medicaid and the Children's Health Insurance Program that would address eligibility and duration of coverage, standardization of covered services, and quality of care and program financing and payment. The statement suggests that implementation of the recommendations would support a higher-quality, more comprehensive, family-oriented, and

equitable system of care that increases access to services, reduces disparities and state-by-state variations, dismantles structural racism, and improves health outcomes into adulthood. [Read the statement.](#)

NATIONAL POLICY

Fact Sheet: Become an EPSDT Expert

Early and Periodic Screening, Diagnostic, and Treatment (EPSDT) is the mandatory service for Medicaid-eligible children under age 21 that requires state Medicaid programs to cover vision, hearing, dental, and medical screenings and to arrange for corrective treatment that a child needs. To assist advocates, the National Health Law Program has developed a fact sheet that provides an overview of EPSDT, a snapshot of states' performance implementing EPSDT, and data sources that track EPSDT nationally and in each state. [Read the fact sheet.](#)

In Brief

- [SSI, Social Security Benefits Set to Increase](#) – from *Disability Scoop*

CALL FOR PROPOSALS

Reminder: Deadline to Present CYSHCN/Disabilities Work at AMCHP Conference

November 3 is the closing date to submit proposals to present skills-building sessions, workshops, posters, or roundtables at the Association of Maternal and Child Health Programs National Conference in April in Oakland, CA. The conference theme is *Partnering with Purpose*, and Children and Youth with Special Health Care Needs and Disabilities is one of the tracks. [Learn how to apply.](#)

FAMILY ENGAGEMENT

Beyond a Seat at the Table: Design Considerations for Effective Medicaid Community Advisory Committees

To create more responsive services, state Medicaid agencies are increasingly seeking to incorporate members' perspectives into their work through community advisory committees/boards. The Center for Health Care Strategies (CHCS) worked with the California Department of Health Care Services to develop recommendations for the design of its Medi-Cal Member Advisory Committee (MMAC). Key findings from CHCS' reports include promising practices for committee development and sustainability that could be applicable to committees nationwide. Operational support of the MMAC is funded in part by our Foundation. [Read more.](#)

PEDIATRIC PALLIATIVE CARE

Study: What Families Want from Palliative Care

Research reported in *JAMA Pediatrics* examines how parents of children receiving palliative care rank five common goals of care, such as quality of life or comfort. The authors note the importance of reassessing goals with parents over time to guide appropriate clinical intervention. Read [Goals of Care Among Parents of Children Receiving Palliative Care](#).

Webinar: ‘Visualizing Loss’ Films

- DATE** Wednesday, November 8
- TIME** 9 to 10 a.m. Pacific Time
- SPONSOR** Pediatric Palliative Care Coalition
- DETAILS** Bereavement following the death of a child remains largely hidden. Five families created their own videos to share their unique bereavement experiences. This free Firefly Chat will include screening of the films, followed by a panel discussion with the parents and members of the project team. [Read more and register](#).

MENTAL/BEHAVIORAL HEALTH

Webinar Reminder: Leveraging Medicaid to Support Children and Youth Living with Complex Behavioral Needs

- DATE** Wednesday, November 8
- TIME** 10 to 11 a.m. Pacific Time
- SPONSOR** Manatt
- DETAILS** An interactive panel, including state officials, youth advocates with lived experience, and leading clinicians, will discuss actionable strategies to respond effectively to the crisis in youth mental and behavioral health that has been exacerbated by the pandemic. [Read more and register](#).

PUBLIC HEALTH EMERGENCY UNWINDING



- [The Importance of Medicaid Stories: Floridians Share Personal “Unwind Horror Stories” with National Media and US District Court](#) – from the National Health Law Program
- [Unwinding Continuous Coverage](#) – Resources and current state data from the Georgetown Center for Children and Families

- [Medicaid and CHIP Renewals: Reaching Children and Families in School-Based and Early Education and Care Settings](#) (PDF) – from the Centers for Medicare and Medicaid Services

INTELLECTUAL/DEVELOPMENTAL DISABILITIES

- Online registration ends **October 30** for The Arc’s National Convention, which will be held November 6-8 in New Orleans. [Learn more](#).

HEALTH CARE FINANCING



The recording of the Manatt webinar, [Proposed Rules on Medicaid Payments, Access, and Quality - Implications for Health Care Stakeholders](#) now is available.

SPECIAL EDUCATION

- [Ed Department Update of Disability Regulations in Limbo](#) - from *Disability Scoop*
- [Schools Nationwide Report Shortage of Special Educators](#) - from *Disability Scoop*

CALIFORNIA POLICY

Medi-Cal Children’s Health Advisory Panel to Meet

DATE	Thursday, November 2
TIME	10 a.m. to 2 p.m. Pacific Time
LOCATION	The California Endowment, 1414 K Street, Sacramento, or attend virtually.
SPONSOR	Department of Health Care Services
DETAILS	Meeting materials and registration information will be posted on the web page . Advance registration required.

RESOURCES

New National Child Health Data Available

Data on the National Performance Measures and the National Outcome Measures from the 2022 National Survey of Children's Health have been released by the Data Resource Center for Child and Adolescent Health. The National Survey provides data from 54,103 children ages 0-17 years, including children with special health care needs. [Learn more](#) about accessing national, state, and regional data.

In Brief

- The Federal Communications Commission's [Affordable Connectivity Program](#) helps families on Medicaid, SSI, or other programs afford internet service. Monthly discounts on internet access and one-time discounts on computers or other devices are available for those who qualify.

IN THE NEWS

- [NFL Rolls Out Adaptive Apparel for Fans with Disabilities](#)
Disability Scoop, 10/20/23

WE'D LIKE TO HEAR FROM YOU

Let us know what's happening with your organization or family. Email newsletter assistant editor Hannah Au at Hannah.Au@lpfch.org with your news or updates. Or contact newsletter editor: Eileen Walsh at Eileen.Walsh@lpfch.org.

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